Challenges of Living with Cystic Fibrosis (CLCF)

A questionnaire for caregivers of children one year after diagnosis up to 14 years of age

Abridged version

|  |  |
| --- | --- |
| **Name of person completing form** | **Relationship to child with CF** |
| **Name of child with CF** | **Date of Birth of Child with CF**    **\_\_\_\_\_\_/\_\_\_\_\_\_/\_\_\_\_\_**  **Day / Month / Year** |
| **When was your child diagnosed with CF?**    **\_\_\_\_\_\_\_/\_\_\_\_\_\_**  **Month / Year** | **Does your child have a minder or babysitter for part of the day?**  **What nursery/school year/grade is your child in?** |
| **Today’s Date**    **\_\_\_\_\_\_/\_\_\_\_\_\_/\_\_\_\_\_\_**  **Day / Month / Year** | |

*In answering the questions on this and the next page please consider your responses over the past two weeks*

Family Lifestyle

1 2 3 4 5

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**1. How does your family divide childcare relating**

**to CF?** I do it all Equal Shares My partner/others do it all

**2. How would you describe your general family lifestyle?** *(please circle one number)*

**2a** 1 2 3 4 5

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

Relaxed Stressed out

2b 1 2 3 4 5

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

Work together Work as individuals

**3. How well do you feel you are** 1 2 3 4 5

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**juggling the demands of CF with the needs of**

**your family?**

No difficulty A little Marginal Definite Great difficulty

**4) How well do you feel your family** 1 2 3 4 5

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**as a whole is handling the challenges of CF?**

Very at ease Definite Marginal A little Very uneasy

**5) Over the last two weeks, how well has your child been:** *(please tick one)*

Unwell Mostly unwell Mixture of well and unwell Mostly well Well

Child’s Character

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Strongly agree | Agree | Neutral | Disagree | Strongly disagree |
| 6) My child makes more demands on me than I expected | 1 | 2 | 3 | 4 | 5 |
| 7) My child sleeps throughout the night | 1 | 2 | 3 | 4 | 5 |
| 8) My child makes friends easily. | 1 | 2 | 3 | 4 | 5 |
| 9) My child is easily upset by things generally | 1 | 2 | 3 | 4 | 5 |
| 10) My child is very moody | 1 | 2 | 3 | 4 | 5 |
| 11) My child is popular with his/her peers | 1 | 2 | 3 | 4 | 5 |
| 12) My child reacts very strongly when something happens that s/he doesn’t like. | 1 | 2 | 3 | 4 | 5 |
|  | Strongly agree | Agree | Neutral | Disagree | Strongly disagree |

Challenges to Family Life

**13) How supported do you feel by the following groups of people?** (please tick boxes that best reflect your view).

Not at all supported

Very supported

Not at all supported

Very supported

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Family members | 1 | 2 | 3 | 4 |  | CF team | 1 | 2 | 3 | 4 |
| Friends | 1 | 2 | 3 | 4 |  | GP | 1 | 2 | 3 | 4 |
| Another parent whose child has CF | 1 | 2 | 3 | 4 |  | Pharmacy | 1 | 2 | 3 | 4 |

**14) To reduce the risk of cross infection, the CF team advises that people with CF avoid contact with**

**1 2 3 4 5**

**1 2 3 4 5**

**other people with CF. How much does this affect**

**contact with other CF families?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**A** great deal Some Moderate A little Not at all

**15) Caring for a child with CF can involve extra expense. How difficult is it for you to manage this?**

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

Very difficult moderately Not at all difficult

**16) To what extent do you think CF has changed**

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**your work pattern?**

**A** great deal Some Moderate A little Not at all

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**17) How often have you had a disturbed night’s**

**sleep in the past 2 weeks?**

Every night Frequent Some Few No nights

Hopes and Worries

*In answering the questions on this and the next page please consider your responses over the past two weeks*

**18) Some say that living with CF is like a balance of hope and worry:**

**What hopes do you have for your child?**

Not hopeful

Very hopeful

Not hopeful

Very hopeful

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| S/he will adjust well to secondary school | 1 | 2 | 3 | 4 |  | S/he will have a family of his/her own | 1 | 2 | 3 | 4 |
| S/he will go to higher education | 1 | 2 | 3 | 4 |  | S/he will continue to be as well as s/he is now | 1 | 2 | 3 | 4 |
| S/he will have a job | 1 | 2 | 3 | 4 |  | There will be an advance in science that will help my child | 1 | 2 | 3 | 4 |

**1 2 3 4 5**

**19) It is difficult to predict what the future holds**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**in relation to CF. To what extent does this**

**uncertainty affect your family’s approach to life?**

A great deal

Moderately

Not at all

**1 2 3 4 5**

**20) How much does the responsibility**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Moderately |  |  |

**of looking after a child with CF affect you?**

Not at all

A great deal

**21) How much is your child’s growth a worry for you?**

**A) Height? 1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  | A little |  | Not at all |

A great deal

**B) Weight 1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  | A little |  | Not at all |

A great deal

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**22) To what extent are you worried that your child**

**might become infected with pseudomonas when s/he is**

Not at all

Moderately

A great deal

**outside the home, e.g. at friends’ houses, at school?**

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  | Not at all |

**23) How worried are you about a change in your child’s lung function?**

A great deal

CF Routines

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**24) How easy was it to establish the CF care routine**

**after your child was diagnosed?**

Not at all easy

Moderately easy

Very easy

No problem

A constant problem

**25) How much of a problem is it to manage the**

**daily routines for CF now?**

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

a) Mealtimes—maintaining high calorie diet

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

b) Digestion – tummy problems (wind, pain, diarrhoea)

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

c) Taking enzymes/creon

**1 2 3 4 5**

d) Taking vitamins/oral antibiotics

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

e) Doing physiotherapy

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

f) Doing nebulised medications

No problem

A constant problem

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**26) With all the things that need to be done,**

**1 2 3 4 5**

**it may be overwhelming at times. How much**

**has this been true for you over the last 2 weeks?**

Not at all true

Very true

Neutral

**27) Do you think all these treatments for**

**1 2 3 4 5**

**your child are justified?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

Not at all justified justified

Completely justified

Community Support

**28) What quality of relationship do you have**

**1 2 3 4 5**

**with your local GP/surgery?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

Moderately good

Not at all good

Very good

**29) How helpful is your local pharmacist?**

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

Moderately helpful

Not at all helpful

Very helpful

**30) What sort of relationship do you have**

**1 2 3 4 5**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Moderately good |  | Not at all good |

**with your child’s minder/nursery/school?**

Very good

**1 2 3 4 5**

**31) How comfortable are you with how your**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**child’s minder / nursery, or school is in giving**

**medications to your child?**

Moderately comfortable

Very comfortable

Not at all comfortable

CF Clinic

**1 2 3 4 5**

**32) How consistent are the messages you get from**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**different members of the professional team?**

Very consistent

Not at all consistent

Moderately consistent

**33) How much written information would you like**

**1 2 3 4 5**

**To have from the CF team about your child’s**

**condition?**

|  |  |  |  |
| --- | --- | --- | --- |
|  | The same as now |  |  |

Less information

More information

Inpatient and Day Patient Stays

**34) When was the last time your child with CF was**

**admitted to hospital as a day patient or overnight? Month Year**

What was it for?

**35) Did your child have any of the following procedures? Blood taken**

**Insertion of IV line**

**Cough swab**

**An operation**

**Replacing IV line**

1 2 3 4 5

**36) How stressful was this admission for you**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**and your family?**

Very stressful

Not at all stressful

Stressful

CF Treatments

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **37) Over the last two weeks how much has your child needed the following treatments to keep him/her well?** | **SECTION 1A**  **Prescribed?**  *Please tick a circle.*  *If yes, complete*  *Section B & C.* | | | **SECTION 1B**  **Treatment Taken :**  **Time Required**  *Please estimate the time spent doing this treatment* | | **SECTION 1C**  **Treatment** **Taken :**  **Effort Required**  *Please tick the circle that represents the amount of effort required to do each treatment* | | |
| *Please tick one circle next to each question in section A and estimate time taken (section B) and effort (section C) involved* | Yes | Yes but not done | No | Minutes per day doing the  task | Number of days of treatment over past week | Minimal Effort | Moderate Effort | High Effort |
| **Calculating doses** | O | O | O |  |  | O | O | O |
| **Extra day time feeding /calorie** **supplements** | O | O | O |  |  | O | O | O |
| **Inhalers** | O | O | O |  |  | O | O | O |
| **Insulin injections for diabetes** | O | O | O |  |  | O | O | O |
| **IV antibiotics at home** | O | O | O |  |  | O | O | O |
| **IV antibiotics in**  **hospital** | O | O | O |  |  | O | O | O |
| **Nebulised medications:** |  |  |  |  | |  |  |  |
| **Antibiotics** | O | O | O |  |  | O | O | O |
| **DNAse** | O | O | O |  |  | O | O | O |
| **Hypertonic Saline** | O | O | O |  |  | O | O | O |
| **Salbutamol** | O | O | O |  |  | O | O | O |
| **Non-prescribed**  **(alternative remedies e.g., herbal remedies)** |  |  |  |  |  | O | O | O |
| **Oral antibiotics (back-up & specific)** | O | O | O |  |  | O | O | O |
| **Other medicines (lactulose, antacids, vitamins etc)** | O | O | O |  |  | O | O | O |
| **Overnight feeds through a gastrostomy or nasogastric tube** | O | O | O |  |  | O | O | O |
| **Oxygen therapy delivered by mask or nasal specs** | O | O | O |  |  | O | O | O |
| **Pancreatic enzyme**  **Supplements (creon)** | O | O | O |  |  | O | O | O |
| **Physiotherapy** | O | O | O |  |  | O | O | O |
| **Ursodeoxycholic acid (URSO) for liver involvement** | O | O | O |  |  | O | O | O |
| **Collecting & preparing medicines and cleaning equipment** | O | O | O |  |  | O | O | O |

*In answering the questions on this and the next two pages please consider your responses over the past two weeks*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **38) We want to know how hard it has been for YOU to manage these treatments.**  *(Please tick one circle from Section 2A for each treatment type that applies and then consider Section 2B)* | **Section 2A:**  **How hard has it been for YOU to**  **manage these treatments?** | | | | **Section 2B:**  **Please tick the circle next to any treatment that YOU would like to talk about the next time you come to clinic. This may be how it is done or whether it is relevant.** |
| Very Difficult | Somewhat Difficult | Not at all Difficult | Does not apply | Yes, I would like to talk about this treatment at the next clinic or annual review |
| **Extra feeding, calorie supplements** | O | O | O | O |  |
| **Inhalers** | O | O | O | O |  |
| **Insulin injections for diabetes** | O | O | O | O |  |
| **IV antibiotics at home** | O | O | O | O |  |
| **IV antibiotics in hospital** | O | O | O | O |  |
| **Nebulised medications:** |  |  |  |  |  |
| **Antibiotics** | O | O | O | O |  |
| **DNAse** | O | O | O | O |  |
| **Hypertonic Saline** | O | O | O | O |  |
| **Salbutamol** | O | O | O | O |  |
| **Non-prescribed remedies (e.g. alternative remedies)** | O | O | O | O |  |
| **Oral antibiotics (back-up & specific)** | O | O | O | O |  |
| **Other medicines (lactulose, antacids, vitamins etc)** | O | O | O | O |  |
| **Overnight feeds through a gastrostomy or nasogastric tube** | O | O | O | O |  |
| **Oxygen therapy by mask or nasal specs** | O | O | O | O |  |
| **Pancreatic enzyme supplements (creon)** | O | O | O | O |  |
| **Physiotherapy** | O | O | O | O |  |
| **URSO for the liver** | O | O | O | O |  |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **39) How do you think YOUR CHILD has managed these aspects of the CF routine over the last two weeks?**  *(Please tick one circle from Section 3A for each treatment type and then consider Section 3B)* | **Section 3A:**  **How hard has it been for YOUR CHILD to manage these treatments?** | | | | **Section 3B:**  **Please tick the circle next to any treatment that YOUR CHILD would like to talk about the next time you come to clinic. This may be how it is done or whether it is relevant.** |
| Very Difficult | Somewhat Difficult | Not at all Difficult | Does not apply | Yes, my child would like to talk about this treatment at the next clinic or annual review |
| **Extra feeding, calorie supplements** | O | O | O | O |  |
| **Inhalers** | O | O | O | O |  |
| **Insulin injections for diabetes** | O | O | O | O |  |
| **IV antibiotics at home** | O | O | O | O |  |
| **IV antibiotics in hospital** | O | O | O | O |  |
| **Nebulised medications:** |  |  |  |  |  |
| **Antibiotics** | O | O | O | O |  |
| **DNAse** | O | O | O | O |  |
| **Hypertonic Saline** | O | O | O | O |  |
| **Salbutamol** | O | O | O | O |  |
| **Non-prescribed remedies (e.g. alternative remedies)** | O | O | O | O |  |
| **Oral antibiotics (back-up & specific)** | O | O | O | O |  |
| **Other medicines (lactulose, antacids, vitamins etc)** | O | O | O | O |  |
| **Overnight feeds through a gastrostomy or nasogastric tube** | O | O | O | O |  |
| **Oxygen therapy by mask or nasal specs** | O | O | O | O |  |
| **Pancreatic enzyme supplements (creon)** | O | O | O | O |  |
| **Physiotherapy** | O | O | O | O |  |
| **URSO for the liver** | O | O | O | O |  |

THANK YOU

THANK YOU